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Independent Living & Medicaid: Challenges & Opportunities

Introduction

Long-term services and supports (LTSS) refers to a broad range of medical, functional and social services that are needed by individuals who have complex health needs due to aging, chronic illness or disability.

Types of individuals who need LTSS



Elderly, ages 65+



Non-elderly adults with physical disabilities or intellectual and/or developmental disabilities (I/DD), ages 16–64



Children with physical disabilities or I/DD, under 18

The need for LTSS affects individuals of all ages and is generally measured by limitations in one's ability to perform activities of daily living such as eating, bathing, dressing or walking, and activities that allow individuals to live independently in the community, including shopping, housework and meal preparation.¹ LTSS are delivered in a variety of settings, including home- and community-based settings (e.g., adult day services and personal care/homemaker services) and institutional care (e.g., intermediate care facilities for people with intellectual and developmental disabilities and nursing homes).

For many who utilize LTSS, living independently and the opportunity to self-direct needed services are central to their personal satisfaction. For these individuals, home- and community-based services (e.g., adult day services and personal care/homemaker services) are crucial.

Independent living and self-direction are often misunderstood, which can compromise a person's experience. This paper seeks to provide a glimpse into the dynamics of independent living along with some of the challenges people experience when trying to achieve it.

Overview: Defining Independent Living and Those It Serves

The concept of independent living originated in the 1960s when the deinstitutionalization movement took hold. Advocates focused on creating opportunities for people living with disabilities to live safely in the setting of their choosing, providing any necessary supports to live a healthy and meaningful life. As the movement has evolved, the opportunity to live independently has become a goal for older adults as well as for people living with disabilities. Independent living regards individuals living with disabilities as the same as their non-disabled counterparts, enjoying all the same freedoms and civil rights.² Independent living is often defined differently across groups and individuals and does not always mean living alone. Broadly, it means living a life based on individual choice — having the right to succeed, try and fail. Decisions that a younger and/or non-disabled person do not consider — like when to have a meal and what the meal should be, when to get dressed, whether to have a pet, and a long list of other examples — are often used to help define the concept.

Independent living is a fundamentally important concept to most individuals, both non-disabled and those living with disabilities. However, the ability to make one's own choices and live as one sees fit is something that non-disabled individuals may not recognize as an inherent privilege. In today's society, individuals typically have support that can step in during times of need: a spouse might make a meal, a sister helps with organizing and paying bills, a friend drives to an important doctor appointment. And many people live as part of a larger community from which they get some level of social or emotional support on a regular basis. For individuals living with disabilities, however, these supports are a regular but life-changing necessity. Receiving and maintaining sufficient supports to sustain independent living is, all too often, a significant challenge.

Challenges to Achieving Independent Living

In 1999, people living with disabilities received a positive push when the U.S. Supreme Court issued its decision in *Olmstead v. L.C.* In that case, the Supreme Court found that confining people living with disabilities to an institution constitutes discrimination and a violation of the Americans with Disabilities Act.

The Court also said that public entities must provide community-based services to persons living with disabilities when:

- Such services are appropriate
- The affected persons do not oppose community-based treatment
- Community-based services can be reasonably accommodated while taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.³

While the win of *Olmstead* was significant, the third element represents a significant challenge as the limited availability of long-term care supports force many individuals to reside in institutional settings, despite their desire to live independently.



Housing shortages

There is a severe shortage of affordable housing, impacting both people living with disabilities and non-disabled individuals.⁴ This shortage makes housing unaffordable for many, even when living with a roommate or two. Medicaid is unable to pay for room and board or rent for those living outside of institutional settings. Further complicating matters, individuals living with disabilities often require housing that is accessible and locating available housing that is both affordable and accessible can feel like a near impossibility. Funding limitations and low availability of accessible housing result in long waiting lists for publicly funded housing, forcing people to remain in nursing homes or risk homelessness.



HCBS waiting lists and funding limitations

Federal requirements for Medicaid include mandatory nursing facility services, while home- and community-based services (HCBS) are optional,⁵ which has created a bias toward institutional settings since states must cover nursing facility services in order to receive federal funding for Medicaid. To provide HCBS services, states can obtain waivers from CMS. Although all states currently leverage waivers, the waiver design may not include all potentially eligible populations. Additionally, the number of individuals that can be served under the waiver, often referred to as “waiver slots,” is dependent upon a state’s ability to pay its share of the costs. This means that while a person may meet the eligibility requirements for HCBS, they may not be able to enroll for services if all waiver spots are full.



Over 800,000
people currently on waiting lists
for services across the country.⁶

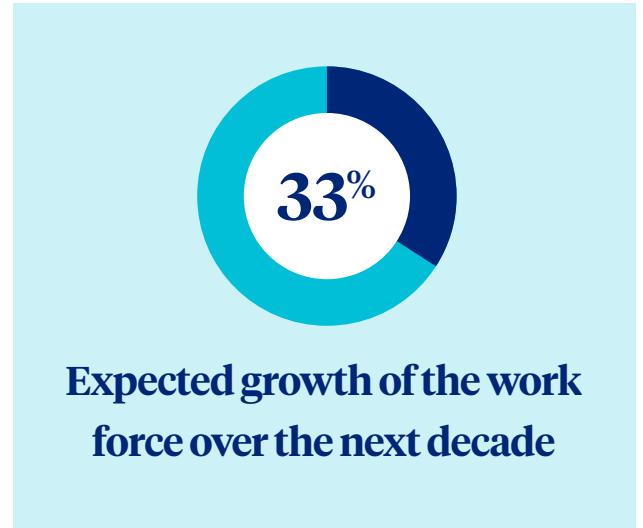
People remain on the waiting list until a waiver space becomes available and waiting list management varies by state.⁷ While on these waiting lists, individuals living with disabilities may receive assistance from family or friends or are forced to continue living in nursing facilities in order to receive services.



Caregiver burnout and capacity constraints

Caregivers provide the assistance that allows individuals to remain safely at home or in the community and are essential to achieving independent living. Caregivers take many forms. In some cases, they are professionals who are paid to provide care, known as direct care workers. In other cases, caregivers are friends or family members, known as natural supports or informal caregivers.

There are currently 2.3 million direct care workers taking care of people at home. The work force is expected to grow by 33% over the next decade, a rate much faster than for other occupations.⁸ This growth is in direct response to the aging of the Baby Boom generation, which will cause the population of adults over age 65 to double from 2016 to 2060. The number of adults over age 85 will nearly triple during the same time period.⁹ Additionally, the number of people willing to enter the direct care workforce is shrinking, in part due to typically low pay and limited, if any, benefits. By 2030, an estimated 6.9 million direct care jobs will need to be backfilled due to current caregivers leaving the industry.¹⁰ With job requirements that are very physically and emotionally demanding as well as the challenges brought about by the COVID-19 public health emergency, this workforce decline is expected to continue, which further complicates access to HCBS.



Unpaid care provided by family or friends, referred to as natural supports, makes up the vast majority of care provided for HCBS in the United States.

In 2017 approximately 41 million unpaid caregivers provided 34 billion hours of care, an estimated value of \$470 billion.¹¹ As of 2020, the number of people providing care to an adult or child with special healthcare needs increased to 53 million.¹²

2017

41 million

unpaid caregivers

2020

53 million

unpaid caregivers

In addition to providing unpaid care, natural supports often have capacity challenges. Caregivers have jobs and their families to raise and they struggle with the physical and emotional demands of being a caregiver. They often experience financial challenges — sometimes due to lost wages when caregiving limits the availability to work or to commit personal resources to provide for the person receiving services. Caregivers report a need for self-care, respite, and opportunities to focus on their own health needs in order to successfully continue caregiving duties.¹³ For many people, unpaid caregivers are the key to remaining safely at home and out of an institution.

The challenges for caregivers are numerous, and outlined in the UnitedHealthcare Community & State National Advisory Board's whitepapers [Addressing Challenges Faced by Family Caregivers](#) and [Addressing Challenges Faced by Professional Caregivers](#). Caregiving was a significant topic for President Biden during his campaign and has been a key focus area for the Biden Administration, including legislation introduced to improve pay and benefits and ease the burdens of family caregivers.

Opportunities for Policy Reform



Address institutional bias

Current scenario: Existing laws require Medicaid to pay for nursing facility services, but home-based services are optional. This structure encourages hospitals to automatically discharge people to a nursing home even when a person utilized HCBS before nursing home admission, as there are no potential HCBS eligibility or waitlist complications, which creates a hospital-to-nursing-home pipeline.¹⁴ Further, for those who do not have a family caregiver and cannot get home-based services due to a waitlist, a nursing home may be the only option that allows a person to have access to bathing, dressing assistance or meals.

Opportunities for policy improvement:

- Develop a permanent benefit construct that provides Medicaid-funded, personal care services, temporary or permanent based on need, to assist individuals with a safe transition from the hospital to home.
- Evaluate permanent adoption of Appendix K waivers that have increased access to home- and community-based services during the public health emergency.
- Consider adopting presumptive eligibility for Medicaid across all populations. Include access to all services for which a person qualifies when using the presumptive eligibility pathway.



Complex eligibility and wait lists

Current scenario: Medicaid eligibility is complicated and varies from state to state. In addition to meeting criteria for general Medicaid eligibility, individuals living with a disability have additional eligibility requirements that are typically more complicated and can vary significantly from state to state. Even once an individual is successfully enrolled in Medicaid, there may be wait lists for services in addition to various state-mandated utilization controls.¹⁵ Each state also creates individual benefit packages available through waivers, meaning the services available to an individual are unique to the state and the waiver for which the person qualifies.

The eligibility requirements and available benefit package changes (sometimes dramatically) from state to state to create an artificial limit on opportunity — once consumers are safely receiving services, they often cannot risk relocating or taking part in any status-changing activity (job, marriage) that could impact their eligibility or waiver position.

Opportunities for policy improvement:

- Encourage states to use additional HCBS Federal Medical Assistance Percentage (FMAP) funding provided through the American Rescue Plan Act (ARPA) to increase eligibility and access to waivers to reduce enrollment challenges and waitlists.
- Make funding increases permanent and include a Maintenance of Eligibility (MOE) requirement that all new funding must supplement, not supplant, state funding.
- Leverage managed care to support comprehensive Medicaid programs that include individuals who are over age 65 and those with disabilities to support navigation and management of state plan and waiver services.
- Allow portability of eligibility criteria and benefit packages, allowing individuals greater freedom to relocate and consider other life changes available to younger and non-disabled individuals.
- Create a minimum package of mandatory benefits that states can add to in order to provide HCBS.



Depleted federal and state staff capacity

The federal focus on HCBS and additional, although temporary, funding are exciting developments. Permanent funding and permanent expansion of HCBS are key advocacy points; however, in order to fully implement new programming, even in a temporary environment, having staff to develop and execute on new plans is critical. Federal and state Medicaid offices are not currently staffed to take on significant new funding and the related planning required.

Opportunities for policy improvement:

- Require some amount of new funding to be used to hire federal and state staff to plan, create, implement and maintain newly developed or expanded programs.
- Provide federal technical assistance to states so that new programs have a faster path to meeting requirements and can be implemented on a shorter timeline.
- Incentivize states to take prompt action to develop plans and implement new programs.

Managed Care Organizations Support of Independent Living

UnitedHealthcare Community & State is a firm supporter of independent living and those who wish to live independently. Across the country UnitedHealthcare partners with Centers for Independent Living (CILs) and relies on the input of the National Council on Independent Living (NCIL) as part of the work of the National Advisory Board.

In addition to supporting CILs, UnitedHealthcare teams are trained on what it means to live independently, supporting independent living choices, and connecting members with supports to aid in accomplishing independent living goals. Team members are trained to exhaust all independent living opportunities before considering institutional placement.

Sources:

- ¹ <https://www.hilltopinstitute.org/wp-content/uploads/publications/LTSSChallengesandOpportunitiesforStatesindifficultBudgetTimes-December2011.pdf>
- ² <https://ncil.org/about/aboutil/>
- ³ https://www.ada.gov/olmstead/olmstead_about.htm
- ⁴ <https://reports.nlihc.org/gap>
- ⁵ <https://www.medicaid.gov/medicaid/benefits/mandatory-optional-medicaid-benefits/index.html>
- ⁶ <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
- ⁷ <https://www.macpac.gov/wp-content/uploads/2020/08/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf>
- ⁸ <https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.html>
- ⁹ <https://phinational.org/policy-research/key-facts-faq/>
- ¹⁰ <https://phinational.org/policy-research/key-facts-faq/>
- ¹¹ <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>
- ¹² <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>
- ¹³ <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>
- ¹⁴ <https://www.healthaffairs.org/do/10.1377/hpb20150917.439553/full/>
- ¹⁵ <https://www.kff.org/report-section/state-variation-in-medicaid-ltss-policy-choices-and-implications-for-upcoming-policy-debates-issue-brief/>

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